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ABSTRACT

This booklet reports the findings of a study that focused on the well-being and lifestyle of 479 families of children (ages 2-17) with Down syndrome (DS) in Finland, Sweden, Norway, Denmark, and Iceland. A comparative study of families of typical children in the Nordic countries was also done. The results of the study indicate that bringing up a child with Down syndrome is usually well managed in the Nordic countries. There was little parental discord that resulted in separations and the families have a good socioeconomic standard. The vast majority of the mothers were relatively satisfied with their lifestyles and maintained an optimistic view of their children's futures, this being particularly true for rural mothers. Usually, the mother provided the extra support system for the child's daily activities though adolescence, because the child with disabilities develops the self-regulative capacities necessary for autonomous activity more slowly than a typical child. The mothers' opportunities for alternative activities were fewer than those of mothers of typical children and do not increase at the same rate as the children attain adolescence. While the vast majority of mothers were relatively satisfied with their life-situation, this satisfaction decreased as their child entered adolescence. (Contains 66 references.) (CR)

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ED 419 365

Research Report

165

Airi Hautamäki

Stress and Stressors in Parenting a Developmentally Delayed Child at Different Life Stages

A Cross-Sectional Nordic Study with a Representative Sample of Nonhandicapped Children.

Department of Teacher Education
University of Helsinki

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Research Report 165

Airi Hautamäki

Stress and Stressors in Parenting a Developmentally Delayed Child at Different Life Stages

A Cross-Sectional Nordic Study with a Representative Sample of Nonhandicapped Children.

The Finnish part (coordinated by Airi Hautamäki) of this Nordic research project has been financially supported by the Nordic School of Public Health in Gothenburg, the Finnish Association for the Mentally Impaired, the Research Foundation of Rinnekoti and the Swedish School of Social Science.

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I would like to dedicate this publication to the brave, courageous and utterly persistent mothers in my study, the invisible heroines of every-day life.

University of Helsinki, Finland, Department of Teacher Education
Research Report 165

Airi Hautamäki

Stress and Stressors in Parenting a Developmentally Delayed Child at Different Life Stages. – A Cross-Sectional Nordic Study with a Representative Sample of Nonhandicapped Children, 69 pages.

Abstract

This study focuses on the well-being and lifestyle of families of 2-17-year-old children with Down syndrome (DS) in Finland, Sweden, Norway, Denmark and Iceland. A comparative study of families of 2-17-year-old nonhandicapped children (NHC) in the Nordic countries was also done. The results indicate that bringing up a child with DS is usually well managed in the Nordic countries. There is little parental discord resulting in separation. DSC-families have a good socioeconomic standard which is also related to SES-differences between the samples compared. The vast majority of mothers are relatively satisfied with their lifestyles and maintain an optimistic view of their children's futures, this being particularly true for rural mothers. The lifestyle of the families with a DS-child in the Nordic countries is circumscribed by the child's disability throughout the family's life cycle. The mother provides the external support system for the child's daily activities throughout his adolescence, because the child develops the self-regulative capacities necessary for autonomous activity more slowly than does a nonhandicapped child. It is difficult for the mother to resolve the conflict between the sustained caretaking responsibilities inherent in mothering her disabled child and her options for other life projects.

According to the life-stage approach to family life, it was assumed that the parents' life-stage expectations mediate the stress they experience. The parents' life-stage expectations are, for example, connected with opportunities to resolve the conflict between caretaking responsibilities and options for other life projects. The DSC-mothers' opportunities for alternative activities are less than those of mothers of nonhandicapped children and the options do not increase at the same rate as the children attain adolescence. The vast majority of DSC-mothers are relatively satisfied with their life-situation, not as much as NHC-mothers and this satisfaction decreases as their child enters adolescence. The DSC-mothers are obliged to play an assertive role in promoting their children's rights. The greater mothering strain inherent in the DSC-mother's role may, over time be a health risk resulting in psychosomatic symptoms, especially in the

metropolitan areas in Finland, Sweden and Norway. On the basis of indirect indicators of the degree of the father's participation in the caretaking responsibilities, it is concluded that the fathers of children with DS in the Nordic countries carry out their part of the caretaking responsibilities. The incidence of the Nordic fathers' long sick-leaves indicates that their health problems are also greater than those of the fathers of nonhandicapped children. If the number of reported psychosomatic symptoms exhibited by siblings is used as an indicator of prolonged stress, siblings of a child with DS in the Nordic countries seem to manifest a moderate stress reaction.

The aim of the social services' interventions is to alleviate maternal strain by offering services to the family and to make it possible for the mother to develop space for other activities in life at the same rate as mothers of nonhandicapped children do, especially as the children develop their age-paced mastery in learning, social activities and work.

Keywords: Parenting, life-stage perspective, mothering strain, stress, psychosomatic symptoms, Down syndrome

Prologue

Winter-child

" - It is a boy.
- Yes?
- He is very tiny – 1,800 grammes.
- Yes?
- But he – he has no feet – "

Anders and Tenna look at each other for a moment. Then the delightful, buoyant Anders lies down across the bed and buries his face in the blanket. Time passes but they do not know what time is.
They clutch each other's hands. They embrace each other. They try to dry the tears from each other's eyes. They do not know what to do, what to believe or to think... only this – that a limitless sorrow has struck them.
Tenna straightens herself. She has had half an hour more time than he. She has had more time than he to absorb the shock. Somehow she has to encourage him, to give him back his strength.

– "In all our crazy life", she says and
looks him straight in his fever-hot face,
"everything has become so petty in
comparison with this one great thing".

She puts her hands around his shoulders.

– "We now have the challenge of our life".

(Dea Trier Mørch 1976, translated by AH)

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1 Background[1]

1.1 A cross-sectional Nordic study with a representative sample of nonhandicapped children

The study is a part of the Nordic research project *Families of Children with Disabilities in the Nordic Countries: A Nordic Research Project for Analysing the Medical and Social Effects of Disability on the Child, the Family and the Society*. The research project was originally initiated by the Nordic School of Public Health in Gothenburg (Köhler 1989a; 1989b; 1990, 7-8), Sweden which also had the task of coordinating the Nordic project with Evy Kollberg, PhD, as the coordinator. The participants of the Nordic research project were Evy Kollberg, PhD, Sweden, Airi Hautamäki, PhD, Finland, Arvid Heiberg, PhD, Norway, Stefan Hreidarsson, PhD, Iceland, Jan Kirkegård, PhD, Denmark. In addition, the participants from each Nordic country were responsible for the data collection in their own countries.

The original approach was social-pediatric (Köhler 1989a; 1989b; 1990, 181) and the large-scale survey research method adopted in the study was largely inspired by epidemiological thinking. In looking at the lifestyles of the Nordic families, the concept of well-being has been defined in terms of the classical definition of having, loving and being (Allardt 1975). The original aim of the research project was to investigate the social, psychological and physical well-being of families with a disabled child in comparison with families with a nonhandicapped child in the Nordic countries (Köhler 1989a; 1989b).

The cross-sectional study reported here focuses on Nordic families with a child with Down syndrome (DS), with the emphasis on the impact that a developmentally delayed child makes on the family's social, psychological and physical well-being and lifestyle as a whole. A control group was included. A comparison study with a representative sample of families of 2-17-year-old nonhandicapped children (NHC) in the Nordic countries was done in 1984-1985 (Köhler 1990, 8-9). Thus, it is possible to compare both family demographics and lifestyles of families with 2-17-year-old children with DS to those of 10,000 families with 2-17-year-old NHC in the Nordic countries.

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1 An edited version of a talk given at ISEC 95, 10.-13. April, 1995, Birmingham, UK (Hautamäki 1995c).

1.2 Stress and factors mediating stress in the family's life cycle

The study reported here centres on stress and stressors that are assumed to be present in the lives of families of developmentally delayed children: Which characteristics in the family's lifestyle mediate the vulnerability to the stress experienced? Additionally, which features of the family are the ones that are related to the alleviation of family members' manifested stress reactions? As the mothers are usually the primary caretakers of the children (Chodorow 1978; 1990; Hautamäki & Slotte 1993; Hautamäki 1995a), they are assumed to be most vulnerable to the presumed stress and the accompanying health risks associated with the sustained caretaking roles inherent in mothering a chronically ill child (Zimmerman 1988; 1992) or a child with a disability. The results of Wishart, Bidder & Gray (1981) suggest that mothers of children with DS and mothers of children whose developmental quotient is less than 65 report significantly higher levels of stress than mothers of nonhandicapped children. Gath (1977), however, did not find any significant differences between the Malaise scores of mothers with children with DS and the mothers of nonhandicapped children when the children were 0-2 years old. Perhaps the stress experienced is related to the age of the children and not the handicap. For this reason, a life stage-perspective was adopted in this study of the family and the parenting of a disabled child.

1.3 A life-stage approach to family life: Do the parents' life-stage expectations mediate stress?

In the present study, as mentioned earlier, the theoretical approach taken for investigating the strain inherent in parenting a child with a disability was a life-stage perspective. It was assumed that the parents' expectations concerning the course of their life mediate stress. In this study it was possible to analyse the relation between the age of the child and the parental stress reactions. The age of the disabled child is not, per se, of interest, but the age of the disabled child may function as a crude indicator of the on-going life-cycle stage of the family. The families are at different stages as regards many life-events that are related to age of the disabled child: among others, choice of school placement, onset of puberty, or potential changes in the provision of social services. The so-called *chronic sorrow* (Wikler, Wasow & Hatfield 1981) inherent in the parental adjustment to their mentally retarded child probably has to do with culturally ascribed standards for the expected developmental pace of children, i.e. the average societal and

behavioural demands placed on the children. The parents' mourning and grief are reactivated by life-events in which the disabled child's abilities are interpreted through the demands implicit in the culturally-determined succession of developmental tasks (for a definition of the term, see Havighurst 1953; Erikson 1950; 1968) for that stage which the child is passing through. The mothers' differing internal(ised) expectations may explain the findings of Gath (1977). Expectations of toddlers' self-regulative capacities, irrespective of disability, differ from the average societal and behavioural demands placed on adolescents.

These age-typical life-events may, in particular, be related to periods of stress and sadness, a phase-triggered reoccurrence of parental grief and mourning (Wikler, Wasow & Hatfield 1981). Because the child is disabled, the mother often, for instance, remains as the external support system throughout his/her adolescence. Unfulfilled parental expectations (at different stages of the family's life cycle) connected to the developmental tasks of the disabled child may contribute to stress. *Chronic sorrow* may emerge as the gap widens between the parents' normative expectations of the child's self-regulative capacities and what the child can, in fact, master on his own.

As Barry Carpenter explains, parents of children with learning difficulties may be more narcissistically vulnerable[2] with regard to their parental identity and self-esteem as their child is growing up and passing through the culturally-determined, successive, developmental stages (Carpenter 1995). Every time the child passes through a respective developmental task-phase, an implicit comparison to children of the same age recurs. As the infant is narcissistically cathected by the parents (Furman 1992, 111), they experience periods of heightened narcissistic vulnerability when the parents' omnipotential dreams and expectations for the child (Solnit & Stark 1961) (and themselves as the ideal parents, a kind of *dreamed-of-parents*) are gradually defined and realised, and the child evolves into the unique individual, separated from his parents, that he is to become. In fact, Furman (1992, 113) states that, as the child grows up, the emphasis of the mother's

2 Applying Kohut's analyses (1971), narcissistic vulnerability is defined as the state of a widening gap or incongruence between one's self, as actually experienced and one's ideal self. It may be described as "*...a painful cognitive-affective condition that subsequently will correlate with the affective experience of shame, that is, the inability to measure up to the required (internally and/or externally) level of competence or performance.*" (Bleiberg 1989, 15).

emotional relationship to her toddler shifts from a narcissistic investment in her infant (beginning with the baby being experienced as an organic part of her body and later as a mental extension of herself) towards an object investment in the child. This is expressed by the mother's developing ability to love her child as a separate being, as a person in his own right.

But if the child is disabled, the parents may be in a more chronic state of heightened narcissistic vulnerability. At the moment of the DS-child's birth, the parents' dreams are abruptly redefined, and they find themselves in the on-going-situation of testing the reality of what the child should be able to do opposed to what he actually can do. The challenge the parents face is learning to compromise their many internal(ised), narcissistically satisfying expectations of the child that are too demanding for him, and still retain the libidinal tie to, object investment in and love for their unique child.

1.4 The conflict between caretaking and other life projects inherent in parenting.

According to the life-stage approach to family life, it is assumed that parents of a child with DS experience chronic sorrow (Wikler, Wasow & Hatfield 1981). The hypothesised time-limited grief and eventual adjustment postulated by Bowlby (1960) and Solnit & Stark (1961) are only the beginning of the parents' life-long struggle of coping with the fact that they have a disabled child. The present study focuses on the life-long nature of adjustment, for instance, the additional caretaking demands and heavier work-load put on parents of a disabled child (See Barnett & Boyce 1995 for the effects of DS-children on the allocation of time to daily activities). It may make the notorious conflict inherent in mothering, that between the caretaking responsibilities and the mother's alternative life projects, almost unsolvable (Gustavsson 1985, 81).

The emphasis on the mother's caretaking responsibilities has deep roots in classic theses of psychoanalytically-oriented developmental psychology. The emphasis on the importance of the early relationship between the mother and her baby is the quintessential tenet of psychoanalytic theory. One of the forerunners of the object relations theory, D.W. Winnicott (1987, 39), states in his definitive thesis that there is no such thing as an infant, only the infant and his mother. It is the mother who provides, through her *holding* function, the continuity-of-being, a sense of coherence and continuity to her infant's self. Without maternal holding the infant would not be able to experience

any continuity of his being. Expressed in more modern terms, the infant would not be able to develop his experience of self-agency (Stern 1991, 89-94), self-coherence (Stern 1991, 95-100), self-affectivity (Stern 1991, 102) and self-history (Stern 1991, 103-106).

Winnicott (1968, 15) emphasises that adequate maternal holding is guaranteed through the expectant mother gradually developing an attitude of *primary maternal preoccupation* towards her baby. Winnicott means by this that the expectant mother increasingly identifies with the child; the baby she is carrying is connected with the idea of an *internal object* (for research concerning the expectant mother's inner representations of her child, see Lebovici 1984). As an enriched and nuanced representation of this fantasised inner object is developed and solidified, the expectant mother becomes more in-turned. Her self-interests, if she has not exercised them very compulsively, diminish and she will *"plunge into this extraordinary condition which is almost like an illness, though it is very much a sign of health"* (Winnicott 1968). The expectant mother will gradually forego her wishes to those of her baby and become willing and able to transfer and reinvest interest from herself to the baby she is carrying.

Winnicott assumes that the infant and his mother constitute, in a psychological sense, a fused dual unity characterised by fluid and permeable boundaries. Mahler, Pine & Bergman (1975, 49) also give due consideration to the infant's psychological vulnerability in the context of this primary caretaking relationship. Along with Winnicott, Mahler, Pine & Bergman (1975, ix) make the assumption of the symbiotic origin of the human condition and of the infant's development, using symbiosis *"to refer to an intrapsychic rather than a behavioural condition; it is thus an inferred state"* (Mahler, Pine & Bergman 1975, 8). Removed from its original biological context, the term symbiosis should be understood metaphorically. The infant's behaviour seems to be characterised by an implicit assumption that he and his mother form a dual unity within one common boundary (Mahler, Pine & Bergman 1975, 44). Symbiosis denotes an assumed state of the infant's fusion with his mother in which the infant's experience of (him)self has not yet differentiated from what does not belong to the self, both being contained in the symbiotic orbit. Thus, the infant's early differentiation from his mother depends on complementary interactions (Bleiberg 1989), a reasonably well-manifested matching of the interactional patterns of the mother and the baby, which may be discerned, for instance, by mutual and responsive cueing. But the infant's early adaptive patterning of his behaviour and his receptive capacities with those of his mother depend on a *good*

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enough holding by the mother, experienced, at this time, in symbiotic terms by the young infant. Interpreted in the terms presented by Mahler, Pine & Bergman (1975), Winnicott's statement refers to the young infant's absolute need for the symbiotic tie to his mother.

Following Tronick (1989), the holding provided by the good enough mother could be characterised by a growing synchronisation between the infant's goal-directed activity and the mother's response to and facilitation of it. The mother validates the infant's self through her need-ameliorative action. Thereby a communication system evolves in which the emotional expressions of the infant and the caregiver allow them to mutually regulate their interactions. Positive development is facilitated if the infant experiences coordinated interactions characterised by opportunities for frequent correction of inevitably occurring interactive errors. The infant learns that he is capable of changing the negative affects that he is experiencing into positive ones by his own communicative efforts, directed towards his mother (parallels may be drawn also to Ainsworth's (Ainsworth, Blehar, Waters & Wall 1978) classic results concerning the link between the mother's sensitivity to her infant's signals and the development of secure attachment, a thesis that has been further substantiated in recent attachment research (Sameroff & Emde 1989; van Ijzendoorn 1995, 397-399)).

Even if the hypothesis of initial symbiosis preceding individuation is not accepted[3] I think it is quite possible to agree with the conclusion of Mahler, Pine and Bergman (1975, 44) about the infant's absolute dependency on his primary caretaker. But, in contrast to Winnicott, Mahler, Pine and Bergman (1975, 44) emphasise that the meaning of this early, sensitively synchronised relationship may be quite different for the adult partner in this dual unity: *"The infant's need for the mother is absolute; the mother's need for the infant is relative."* The mother does not need her infant in same way as the child needs her. The relationship between the mother and the infant is not, as Winnicott seems to assume, quite symmetrical (for an interesting discussion on this topic, see Bjerrum Nielsen & Rudberg 1991, 43-45).

This partial asymmetry may be highlighted by transposing Winnicott's question: Is there such a thing as the mother? Is there only a mother and her infant, the infant molding his mother into motherhood and the symbiotic

3 Stern (1991, 150-151), emphasises the opposite direction in the ontogenetic development, that of the infant developing from rudimentary forms of (emergent and core) self towards increasing interconnectedness.

relationship he needs? As studies on maternal bonding with the newborn infant indicate (Klaus & Kennell 1982), the infant provides the mother with a part of the affectively arousing stimuli for her development into motherhood, the maternal caretaking skills being, in the terms of Wygotski (1974, 236-238), in the zone of proximal development of the mother. But the woman does exist before the birth of the baby, often quite oriented towards other life projects and after the child is born she will still have other interests and desires besides her child. In contrast to the infant, the mother is an adult person, already socialised to the world *outside* their relationship. Although the relationship with the baby is usually her most important one, it is only a part of the mother's world and her social relationships. Thus, not even the needs of the good-enough mother can be assumed to be perfectly symmetrical with those of her infant, an assumption that Winnicott seems to cherish (Bjerrum Nielsen & Rudberg 1991, 44). This assumption of symmetry has all too often been paralleled by the idea that a good mother-infant relationship requires that the needs of the mother and the baby should be almost identical, when, in fact, the interests of the mother seem to be reduced to those of her baby. Consequently, potential conflicts between the interests of the infant and the mother are easily seen as anomalies of the mother-child relationship[4] rather than inherent in the relationship.

1.5 The relational structure of the feminine psyche

Winnicott (1987), in accordance with a traditional view of women, praises the plasticity of the feminine psyche that allows the woman to shift her attention from other life projects to a total pre-occupation with her baby. A more modern construct for explaining the plasticity and the relational

4 In acknowledging the woman's (right to) desires of her own, the opposite danger should, however, be avoided, that of reducing the needs of the infant to what seems to be required by the necessities of maternal emancipation (Bjerrum Nielsen et al. 1991, 44-45). In the name of maternal emancipation the observations of developmental psychological research on what the infant needs (and what the consequences are if his needs for attachment are not met), may be ignored, as these conclusions, if taken seriously, seem to have potential repressive effects on female emancipation in a culture in which the woman is the primary caretaker. The crucial point is, however, to recognise clearly the potential conflict existing between the interests of the child and those of the mother. Every mother is obliged, in the course of her own life-span, to make reappraisals from time to time concerning the priorities of how to solve the conflict and to navigate between the Skylla of the interests of her child and the Karybdis of her self-interests, in a way that betrays neither.

structure of the feminine psyche is *self in relation* postulated by Jean Baker Miller (1976). It is a mental representation of the self which is characterised by more permeable boundaries and a more encompassing sense of the self (Miller 1990, 441) in contrast to the more bounded self encouraged in males (Hautamäki 1995a, 45). Carina Mustelin (1992) calls this the positional self of the male aiming at separateness, autonomy and a sense of agency, which is presumed to originate from the boy's early disidentification from his mother (Hautamäki 1995a, 34-36). The concept of *self in relation* emphasises *"the extraordinarily important character of the interaction – that of attending to and responding to the other"* (Miller 1990, 440) and is defined in today's gender division of labour as primarily feminine. It is the cultural role of women to attend to another's needs and this action: *"... is also the basis of all continuing psychological growth, i.e., all growth occurs within emotional connections, not separate from them."* (Miller 1990, 440-441).

One should, however, recognise, that there are two sides to the coin in postulating the *self in relation* as the core of female identity (Hautamäki 1995a, 46). These two aspects relate to contextual factors. Different contexts (on the one hand, child-rearing as a part of more expressive family roles and, on the other, more instrumental behaviour in the world of work, are connected to different types of temporality, cyclical vs. linear time (Kristeva 1990, 377-378)) put different demands on individuals functioning in those contexts and ultimately influence the value judgements which define the optimal personality development of those persons. In one sense, a woman's less restricted and more encompassing self facilitates, according to Ruddick (1990), maternal thinking, which is the fertile ground and perhaps the necessary condition for caretaking tasks, e.g. good enough mothering (Winnicott 1987). It enables a woman to both enjoy and endure the long-term dependence of the children (to contain the fetus in her womb and the young infant's total dependence on her) and to willingly attend to their needs. In another sense, a risk inherent in female identity development is the tendency, described by Chodorow (1978; 1990), to be caught in relationships which mirror similarities stemming from asymmetrical family structures characterised by unavailable fathers. This may be manifested in a woman's tendency to relinquish her autonomy, will and desire (Hautamäki 1995a)[5].

5 Jack (1991) has empirically analysed the risk inherent in female identity development by creating a model of gender-specific cognitive schemas of intimacy (continued...)

For Scandinavian women, full-time or part-time work has been a long tradition, even for mothers of toddlers. Therefore, for them, it is not a question of shifting attention totally from other life projects to exclusive motherhood, although maternity will to some degree, bring about the notoriously problematic conflict between mothering the child and the time available for other life projects. However, if the child is disabled, the greater-than-average caretaking responsibility will markedly reduce the mother's alternative options for action (Barnett & Boyce 1995). Bradshaw & Lawton (1978) conclude that the children's requirements are related to mothers having higher Malaise scores. However, the crucial point is that only if the mother feels that her leisure and social activities are restricted, and if she feels dissatisfied with her family life and her role as a housewife, will she experience more stress (Byrne & Cunningham 1985, 850). Subjective feelings of restriction are probably also connected with the mother's internal(ised) expectations of the child's development in relation to the life-cycle phase of the family.

1.6 Self in relation – silencing the self?

In terms of the life-stage approach of this study, it was assumed that the experience of stress has to do with these expectations; a toddler or a preschool-aged child, be he disabled or not, will impose many restrictions on the mother's life, but these demands are in accordance with the expectations of the average mother. Winnicott (1968, 15) succinctly expresses the consequences of the child's growing mastery for his mother: *"It is part of the normal process that the mother recovers her self-interest, and does so at the rate which her infant can allow her to do so."* But if the child is disabled, the mother often remains as the self-regulating other throughout his adolescence. The additional burden of caring for the disabled child restricts the mother's opportunities for taking part in and developing alternative life projects. I assume that if it is not possible for the mother to

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5 (...continued)
associated with depression in women and an instrument, the Silencing the Self Scale (STSS), to measure these schemas. The theory suggests (Jack & Dill 1992, 98): *"...that cognitive schemas about how to create and maintain safe, intimate relationships lead women to silence certain feelings, thoughts and actions. This self-silencing contributes to a fall in self-esteem and feelings of a* 'loss of self' *as a woman experiences, over time, the self-negation required to bring herself into line with schemas directing feminine behaviour."*

satisfactorily resolve the conflict between the caretaking responsibilities and the options for other activities (ranging from full-time work to leisure time activities) and gradually, in a quite natural way, *recover her self-interest*, then the unresolved conflict, in the long run, may result in stress. I have modified a model proposed by Gustavsson (1985, 180-182) to illustrate this developmental sequence of how Swedish mothers sought initial solutions to the above-mentioned conflict, gradually rejected the first ones and developed their own, personal solutions for living with their disabled child.

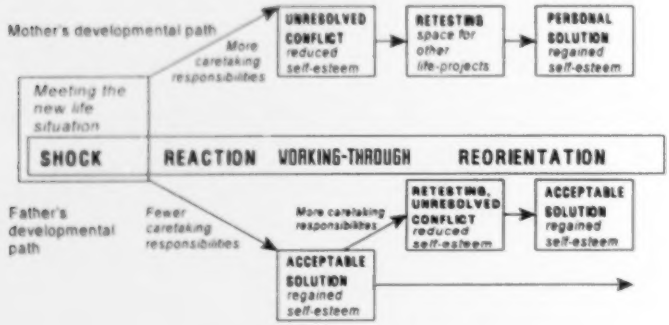

FIGURE 1. Parents' adjustment to and working-through the conflict between caretaking responsibilities and other life-projects.

The discovery of the child's disability shattered the parents' expectations of their parenthood; that they would be the ideal parents of the dreamed-of-baby (Solnit & Stark 1961). In the MEETING THE NEW LIFE SITUATION -phase, the reality of the practical consequences of the child's disability and the resulting conflict between the parents' personal interests and those of the child emerged. The first solution to the conflict arrived at by the mothers studied by Gustavsson (1985) was characterised by abstaining from any other life projects; the mothers stayed at home abandoning their earlier plans and ambitions in order to provide for and look after their child. One may hypothesise that the first solution, the mother totally devoting herself and her time to the child, was not only the appropriate reaction of a sensitive mother to the needs of her disabled infant, but also may have been an attempt on the part of the mother to heal and to restore her partially damaged self-image of herself as a mother. Because of the huge disappointment and accompanying feelings of guilt the mother perhaps overcompensated for a period of time

and then gradually realized what had happened to her and her child. This may have given her motivation for quite a while.

However, the first solution was unworkable; the mothers became frustrated and exhausted, in other words, *hit the wall* (**unresolved conflict**). The first solution restricted excessively the mothers' options for maintaining their self-esteem in other areas of activity in their lives and they moved on and tested solutions to the conflict that would neither betray their child nor themselves (**retesting**). Usually the new solution presupposed that some of the caretaking responsibilities would be delegated to the father or to the social services system. On the basis of this model, it may be assumed that the mother of the disabled child will experience pronounced stress only if the conflict remains unresolved, as the child grows up. Concomitantly, she sees her contemporaries and realizes that she will never have what they have.

The Swedish fathers usually followed quite a different path than the mothers in working through the conflict. Their first solution was characterised by giving total priority to their work and abstaining from any caretaking responsibilities. As the mothers were retesting their first solutions, the fathers usually became involved. Gradually they assumed some of the care for their disabled child and this initiated the hard-to-solve conflict between caretaking responsibilities and other life projects for them, too. The fathers also had to cope with the conflict and develop new priorities. Thus, it may be assumed that the fathers experienced stress later than the mothers, particularly if they had difficulties in resolving the conflict between their perceived caretaking responsibilities and options for other life projects.

2 Method

2.1 Procedure and instruments

In 1984, a postal questionnaire was distributed to a sample of families with 2-17-year-old nonhandicapped children (N = 10 000) representing each of the Nordic countries (Sweden, Norway, Denmark, Finland and Iceland). In 1991, detailed questionnaires were administered to a sample of families with a 2-17-year-old child with DS (N = 479) in these same countries in order to obtain comparable data on families with a child with mental retardation. Down syndrome was chosen because it is reliably identified already at birth. The parents (usually the mother) responded anonymously to the questionnaire.

The criteria for inclusion in the sample were:

- established diagnosis of Down syndrome in the child
- age of the child between 2 and 17 years
- place of residence: Both urban and rural families were represented in the sample.

The study consisted of three questionnaires:

1) QUESTIONNAIRE A (parents of both nonhandicapped children and children with Down syndrome answered the questionnaire):
   - 75 general questions concerning the SES and well-being of the family
2) QUESTIONNAIRE B (parents of children with DS answered the questionnaire):
   - 30 questions and rating scales specifically tailored to families with a disabled child.
3) QUESTIONNAIRE C (parents of children with DS answered the questionnaire):
   - 26 questions and rating scales specifically mapping presumed problems accompanying raising a child with DS.

One reminder letter was sent six weeks after the first questionnaire. No telephone interviews were done. In Finland, two respondents telephoned the researcher to state that they did not want to participate in the study and gave the reasons why. The reasons given seemed to be connected with a state of still unresolved mourning. The two respondents stressed that answering the questionnaire would reactivate too many painful feelings, and they did not feel that they had enough strength or motivation for the task. The researcher respected their decision and did not push them to answer the questionnaire nor probe for reasons other than those given.

The final Nordic sample was N = 479, and the average return rate exceeded 70 % in the Nordic countries, Finland and Sweden having the highest rates, 79 % each.

Some health indicators were used in the study to measure the assumed outcome of prolonged stress. The mother was the respondent to all questions.
Regarding the mother:
a) the number and type of psychosomatic symptoms, e.g. headache, sleeplessness, stomach troubles, back pains, lack of appetite;
b) the number of short and long sick-leaves taken during the past 12 months.
Regarding the father:
The number of short and long sick-leaves taken in the past 12 months.

The age of the child was used as a crude indicator of the life-cycle stage of the family. The children were divided into three age groups:
a) Pre-school-children, aged 2-6 years
b) Children in their early school-years, aged 7-12 years
c) Adolescents, aged 13-17 years.

2.2 Sample: Family demographics of 2-17-year-old children with DS compared to those with nonhandicapped children.

A demographic comparison was made of families with 2-17-year-old children with DS to those of 10 000 families with 2-17-year-old non-handicapped children in the Nordic countries.

In terms of family demographics, the SES of the DSC-families was higher than that of families with nonhandicapped children (Hautamäki 1995b), especially regarding the mother's and the father's educational level and the socioeconomic status (in terms of parents' professions, see Table 1). It is important to note the differences in the mother's educational levels because this permeates all the socialisation practices of the home (Gecas 1979; Gray & Wandersman 1980, 1006; Hautamäki 1982) related as it is to the mother's feelings of control over her life and her child's development. Family finances did not, however, differ. These educational and socioeconomic differences between the DSC- and NHC-samples were probably due to a slight over-representation of families from urban areas (especially Finland and Sweden) caused by the sampling procedures used for the DSC-sample.

Studies have suggested that the stress associated with additional caretaking responsibilities would lead to higher-than-normal levels of divorce in families with mentally retarded children (Gath 1977). In this Nordic DSC-sample, the proportion of single-parent to two-parent families was about the same as in the Nordic NHC-sample (Hautamäki 1995b, see Table 1). The presence of a child with DS did, however, affect the mother's, but not the father's, working hours. Significantly fewer mothers of children with DS in the Nordic countries had full-time jobs. Instead they worked part-time or were full-time housewives.

Thus, with the exception of the mother's age and working hours, the differences found between the two samples probably reflect differences in sampling procedures rather than real differences between the populations studied.

FAMILY CHARACTERISTICS	DS	NHC	X^2
Mother's education			
Low-level education (completed compulsory education)	52.1	70.3	66.68***
High-level education (completed some further education)	47.9	29.7	
Age			
< 35	27.9	39.8	26.21**
> 35	72.1	60.2	
Employment			
Full-time work	35.8	50.0	35.32***
Part-time work	38.5	31.3	
Housewife	25.7	18.7	
Father's education			
Low-level education (completed compulsory education)	56.8	69.5	29.52***
High-level education (completed some further education)	43.2	30.5	

FAMILY CHARACTERISTICS	DS	NHC	X^2
Employment			
Full-time work	85.7	82.7	4.03
Part-time work	7.4	10.5	
Not working	6.9	6.8	
Family residential area			
Metropolitan area (including suburbs)	48.9	33.7	46.23***
Densely populated area (>3000 inhabitants)	23.7	33.8	
Scarcely populated area (<3000 inhabitants)	27.4	32.5	
Socio-economic status			
Working class (blue-collar)	27.2	37.9	16.32***
Civil-servants (white-collar)	72.8	62.1	
Family finances			
Low-income	46.4	44.9	0.40
High-income	53.6	55.1	
No. of parents in the household			
Two-parent family	90.6	91.8	0.86
Single-parent family	9.4	8.2	
No. of children in the household			
One child	23.4	25.0	9.05*
Two children	40.1	44.8	
Three or more children	36.5	30.1	

* $p < 0.01$, ** $p < 0.001$, *** $p < 0.0001$

TABLE 1. Family demographics of 2-17-year-old children with Down syndrome (N = 479) and nonhandicapped children (N = 10600), (%).

2.3 Analyses

The effects of a child with DS on parental well-being, especially the mother's health and the family's lifestyle were estimated by a two-way analysis of variance. The mother's reported psychosomatic symptoms were estimated using two factors:

1) Presence of a child with DS in the family:
   a) presence of a child with DS in the family
   b) only nonhandicapped children in the family,
2) The age of the child with DS:
   a) pre-school-children, aged 2-6 years
   b) children in their early school-years, aged 7-12 years
   c) adolescents, aged 13-17 years.

Full factorial models were estimated which allowed testing for significant interactions between the effect of a child with DS and the other factor.

3 Results

3.1 The mother's reported psychosomatic symptoms and socio-economic status

The number of reported psychosomatic symptoms (once a week or once in two weeks) of mothers of children with DS was greater than for mothers of nonhandicapped children (see Table 2). Fewer mothers of children with DS were without any psychosomatic symptoms and more of them reportedly suffered from two or more psychosomatic symptoms than did mothers of nonhandicapped children (Hautamäki 1995c).

No. of psycho-somatic symptoms	Mothers of DS-children	Mothers of NH-children	X^2
Two or more	26.1	17.7	21.84***
One	23.4	26.0	
None	50.5	56.3	

* p < 0.01, ** p < 0.001, *** p < 0.0001

TABLE 2. The number of reported psychosomatic symptoms among mothers of DS- and nonhandicapped children in the Nordic countries (N = 479 and 9039, respectively), (%).

The percentage of women who reported no psychosomatic symptoms is related to SES and parenthood (see Table 3). The answer *"No psychosomatic symptoms"* was more frequently given by rural than urban mothers of a DS-child, by mothers who were well-educated, were working full-time and had white-collar jobs with high-level incomes. Mothers from two-parent families reported having no psychosomatic symptoms more often than mothers from one-parent families. The percentage of women who reported no psychosomatic symptoms is, however, neither related to the mother's age nor to the number of children.

SOCIAL BACKGROUND	%	X^2
[redacted]		
Metropolitan area (including suburbs)	44.4	9.33 (n.s.)
Densely populated area (>3000 inhabitants)	43.5	
Scarcely populated area (<3000 inhabitants)	59.2	

SOCIAL BACKGROUND	%	X^2
Mother's education		
Low-level education (completed compulsory education	44.8	3.77 (n.s.)
High-level education (completed further education	52.6	
Socio-economic status		
Working class (blue-collar)	41.5	2.56 (n.s.)
Civil-servants (white-collar)	50.8	
Family finances		
Low-income	41.5	8.04 (n.s.)
High-income	54.1	
No. of parents in the household		
Two-parent family	49.6	6.32 (n.s.)
Single-parent family	34.9	
Mother's employment		
Full-time work	52.9	10.61 (n.s.)
Part-time work	47.9	
Housewife	46.0	

* $p < 0.01$, ** $p < 0.001$, *** $p < 0.0001$

TABLE 3. Number of mothers of children with DS in the Nordic countries reporting no psychosomatic symptoms in relation to social background characteristics (N = 479), (%).

The total number of sick-leaves taken did not differ between the two groups of parents, but the number of long sick-leaves (more than two weeks) for parents of DS- and NH-children did differ significantly (see Table 4).

	Long sick-leaves (>two weeks)	Short sick-leaves (<two weeks)	X^2
DSC-sample	42.6	57.4	27.97***
NHC-sample	24.0	76.0	

* p < 0.01, ** p < 0.001, *** p < 0.0001

TABLE 4. The number of sick-leaves taken by mothers of DS- and NH-children over the past 12 months (N = 155 and 5478, respectively), (%).

	Long sick-leaves (>two weeks)	Short sick-leaves (<two weeks)	X^2
DSC-sample	44.4	55.6	35.32***
NHC-sample	21.8	78.2	

* p < 0.01, ** p < 0.001, *** p < 0.0001

TABLE 5. The number of sick-leaves taken by fathers of DS- and NH-children over the past 12 months (N = 124 and 5073, respectively), (%).

In interpreting the differences in sick-leaves between the two groups, the time-lag between the samples collected should be noted. **Taking sick-leaves in general** is not only related to the frequency of illness, but also to the legal egilibility and the prevailing attitudes towards taking them. **Long sick-leaves** are, however, related to more serious health problems. As there are no differences between DSC- and NHC-parents in regard to the percentages of sick-leaves in general, but there are significant differences when it comes to long sick-leaves, this may indicate that the life-situation of DSC-parents is, in general, more strained. Could the more frequent long sick-leaves taken by DSC-parents indicate that they try to cope with a more strained life-situation until they are on the verge of collapse and thus need a longer period of time to recuperate?

3.2 The mother's reported psychosomatic symptoms in relation to the age of the child

One factor that is assumed to mediate the stress experienced by the mother is the age of the child connected as it is with the parents' life-stage

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expectations and expectations in regard to the child's developing competencies. The number of the mother's reported psychosomatic symptoms was explained by the type of family (DSC-NHC, $F = 18.51$, $p < .000$) and the age of the child (1 = 2-6-year-olds, 2 = 7-12-year-olds, 3 = 13-17-year-olds, $F = 4.37$, $p < .013$, see Figure 2). The number of psychosomatic symptoms reported by a mother of a child with DS was higher in all age groups and increased more rapidly, as the child reached adolescence, than for mothers of nonhandicapped children.

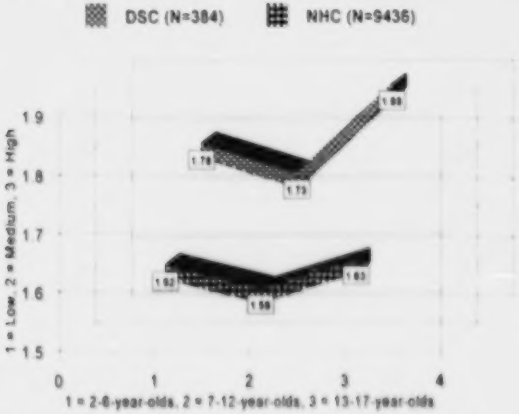

FIGURE 2. Relationship between the level of mother's reported psychosomatic symptoms (N = 384 and 9436, respectively) and child's age

This result is discussed from different points of view in the next part of this paper.

3.3 Diminishing expectations - the answer to dreams realised in different ways in various ecological contexts?

Firstly, the result was examined in terms of diminishing maternal expectations as the child grew up, in accordance with the concept of *chronic sorrow* postulated by Wikler, Wasow & Hatfield (1981). The DSC-mothers' expectations for the futures of their preschool-aged children were, in general, optimististic. However, their expectations in regard to the future of the school-aged child, and, in particular, the adolescent child became more

pessimistic. The mothers did not believe that the child could live an independent adult life without the help of outside support systems (see Figure 3). According to the analysis of variance, the increasing age of the child explained the diminution of expectations ($F = 5.67$, $p < .004$). It might be hypothesized that, as the child grows up, temporary gaps between what the mother expects the child to master on his own and the level of the child's self-regulated activity appear. In the context of each developmental task, the mother's culturally defined and established expectations are contrasted with the child's real capabilities. These periods of diminishing expectations may increase the amount of stress the mother experiences.

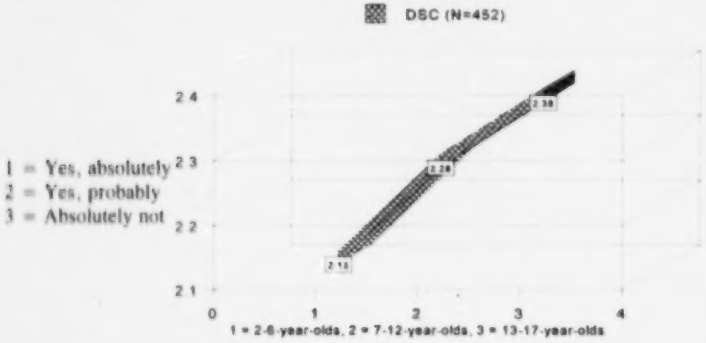

FIGURE 3. DSC-mothers' responses to the question: *"Will your child live an independent adult life?"* (N = 452)

In particular, lower expectations of the DS-child's ability to live an independent life were typical of urban mothers. A comparable decrease was not found among rural mothers of children with DS (Hautamäki 1995b), whose expectations of an independent adult life for their children were generally more optimistic. The rural mothers also regarded their children's disability as less serious than the average urban mother (see Figure 4).

According to the analysis of variance, the residential area was the factor contributing most to the mothers' conception of Down syndrome ($F = 5.92$, $p < .003$). The different ecological contexts of rural and urban environments may mediate the reaction to the child's disability. According to the ecological psychological approach (Bronfenbrenner 1977, 1979), characteristics of the larger environment have an impact on proximal events

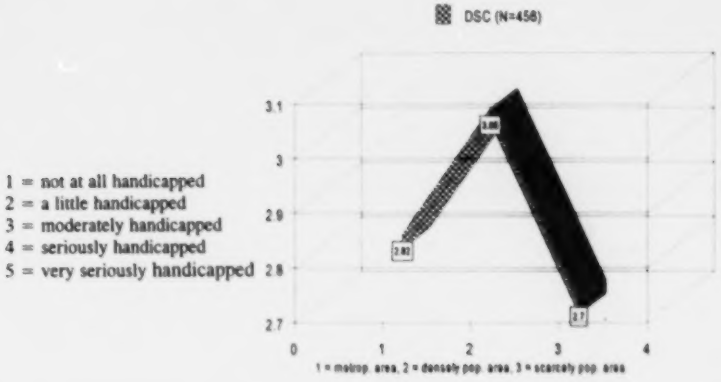

FIGURE 4. DSC-mothers' perceptions of the seriousness of their child's disability (N = 456)

within the immediate setting. One such mediating factor may be the underlying concepts of child-rearing. Gunilla Hallden (1992) makes the distinction between two ways of viewing child-rearing: as *being* or as a *project*. One might hypothesise that the more fatalistic view of the child and his development, inherent in the *being* concept of child-rearing, makes a child's disability easier, in a narcissistic sense, to endure. But if the child is conceptualised as a developmental project, mainly regulated by the goal-directed and deliberate efforts of more highly educated parents, then the disability may be interpreted as a greater narcissistic blow to the presumed concept of *good parenthood* desired by many parents, particularly those living in urban areas?

3.4 Effects of regional differences on reported psychosomatic symptoms of mothers of DS- and NH-children

The ecological psychological approach (Bronfenbrenner 1977; 1979) was further studied by analysing the health of urban and rural mothers. The ecological context seemed to be important for the frequency of reported psychosomatic symptoms of mothers of children with DS. The differences between DSC- and NHC-mothers' psychosomatic symptoms were typical for the metropolitan and densely populated areas, but less so for sparsely

populated areas in the Nordic countries (family type being the explaining factor, $F = 22.20$, $p < .000$, in addition, interaction between the family type and residential area, $F = 3.26$, $p < .039$, Figure 5). The DSC-mothers seemed to suffer more from psychosomatic symptoms in the metropolitan and densely populated areas in these countries. This trend is particularly typical of Swedish, Finnish and Norwegian mothers of children with DS (Hautamäki 1995b).

Is it futile, feudal nostalgia, in the wake of Ferdinand Tönnies' (Tönnies 1887) concept of *Gemeinshaft*, to conclude that there seem to be factors in the families' lifestyles in scarcely populated Nordic areas which seem to buffer the strain of mothering? Is the disabled child, for instance, more easily integrated into the daily activities of the parents on a farm, and, generally, into the social activities of the neighbourhood? Do the parents living in rural and urban environments in the Nordic countries define and experience the meaning of the child's disability differently on the basis of differing child-rearing ideologies, that is, child-rearing as being rather than as a project (Hallden 1992), whereby the child's disability is less narcissistically threatening to the internal(ised) images of good enough parenthood (complemented, of course, by an idea of good-enough-children) desired and sought by the parents? Or does it have to do with a vital fatalistic view that rural dwellers have towards life?

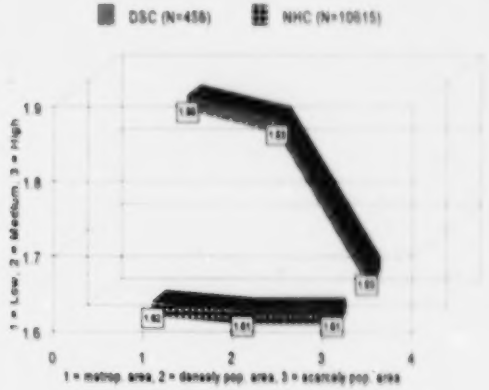

FIGURE 5. Relationship between mothers' reported psychosomatic symptoms and regional differences (N = 456 and 10615, respectively)

3.5 The mother acting as the external support system of the child's daily activities

The results were also examined on the basis of the increased caretaking responsibilities of the mother of a child with DS. Usually the mother is the one who acts as the self-regulating other of the child's daily activities, because the child does not develop the self-regulative capacities necessary for autonomous activity (Hautamäki 1993). A variable concerning maternal guidance was constructed (a sum of how often the mother plays with her child, goes to the theatre or to the cinema with the child, does home-work with the child, reads to the child, or participates in hobbies with the child). The incidence of maternal guidance of children with DS did not differ from that of nonhandicapped children during the children's preschool- and early school-years. However, as the children became adolescents, the need for maternal guidance decreased more rapidly for nonhandicapped children than for children with disabilities. Obviously these children needed their mother for initiating, maintaining and monitoring their activities (the main effects were the child's age, $F = 1304.07$, $p < .000$, and the family type $F = 18.52$, $p < .000$ and, plus, interaction between variables, $F = 42.63$, $p < .000$, see Figure 6).

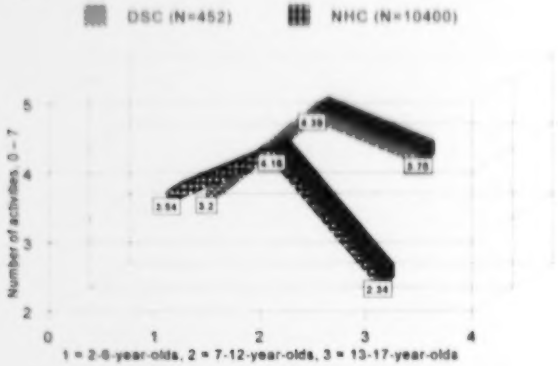

FIGURE 6. Incidence of maternally-guided activities in relation to the child's age for mothers of DSC and NHC (N = 452 and 10400, respectively)

A sum of the variables was also constructed for the child's independent leisure time activities (the child goes to the theatre or cinema, plays, reads, does sports, listens to music, participates in hobbies or takes part in social

contacts). The differences between nonhandicapped and children with DS increased rapidly from the early school-years onward (the main effects were the child's age, $F = 2074.32$, $p < .000$, and the type of family, $F = 178.39$, $p < .000$, plus, interaction $F = 19.55$, $p < .000$, see Figure 7). The results show that the mother of a child with DS serves as the external support system for the child's leisure time activities throughout his adolescence to a greater extent than the mother of a nonhandicapped child.

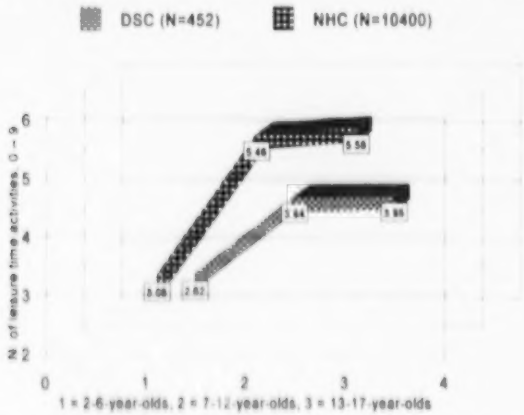

FIGURE 7. Number of DSC- and NHC-children's independent leisure time activities in relation to the age of the children (N = 452 and 10400, respectively)

3.6 The mothers' restricted leisure as an indicator of the conflict between caretaking responsibilities and alternative life projects

According to the life-stage approach to family life, the parents' life-stage expectations and expectations in regard to the child's developing competencies may mediate stress. It may be hypothesised that the increase in psychosomatic symptoms reported by mothers of school-aged children is related to the continuing constriction of opportunities for alternative life projects in work, in leisure and in social activities. Lastly, when the child goes to school, the mother's internal(ised) expectations concerning the child's growing independence in learning and social activities will probably conflict with what the child is capable of managing on his own. The mother does not expect herself to be constrained in the same way by a school-aged

child as by a toddler. It is probably the mother's expectations of an increasing degree of freedom in her life that changes her interpretations of her life situation and thus the emerging feelings of restriction may promote stress.

A sum of the variables consisting of the mother's leisure time activities (hobbies ranging from cultural pursuits to sports, social activities, participation in educational courses, trade union activities) was constructed. Leisure time activities of the mothers of nonhandicapped children steadily increased during the child's early school-years, as he/she became more autonomous and the mother had the opportunity to enlarge the scope of her leisure time activities. Thus, the differences between the DSC- and NHC-mothers' leisure time activities were most pronounced among 7-12-year-old children, becoming more equal during the children's adolescence (the main effects were type of family, $F = 24.28$, $p < .000$ and the child's age, $F = 51.15$, $p < .000$, see Figure 8).

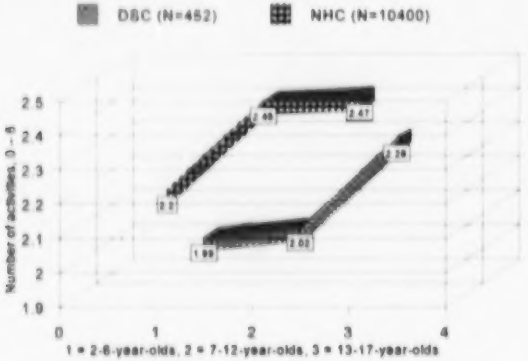

FIGURE 8. Sum of the DSC- and NHC-mothers' leisure time activities in relation to the age of the child (N = 452 and 10400, respectively)

Were the mothers satisfied with their amount of leisure time? The NHC-mothers' satisfaction with their leisure grew steadily from a higher-than-average level when the children were preschool-aged, to a high level of satisfaction, as the children approached adolescence. The DSC-mothers stayed at an average level of satisfaction and their satisfaction differed markedly from the mothers of nonhandicapped adolescent children (the main effects were the child's age, $F = 79.26$, $p < .000$, and the family type, F

= 50.97, $p < .000$, plus, interaction, $F = 4.26$, $p < .014$). Thus, there seemed to be a growing dissatisfaction that may be related to the DSC-mothers' unmet expectations of gradually increasing opportunities for leisure time activities (see Figure 9).

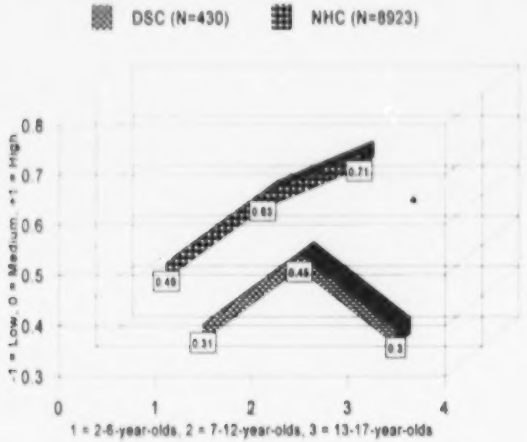

FIGURE 9. DSC- and NHC-mothers' satisfaction with opportunities for leisure time in relation to the age of the child (N = 430 and 8923, respectively).

3.7 The mothers' satisfaction with their family situation

The parents of children with DS also had fewer opportunities to spend leisure time together in activities outside the home, without their children. In families with a nonhandicapped child, the parents' shared activities steadily increased as the child grew up, while the increase was slower in families with a child with DS. These differences did not decrease even during the child's adolescence (the main effects were the family type, $F = 51.47$, $p < .000$, and the child's age, $F = 441.02$, $p < .000$, plus interaction, $F = 8.49$, $p < .000$, see Figure 10).

Were the mothers satisfied with their family situation and the opportunities for joint activities with their husbands (see Figure 11)? On average, the

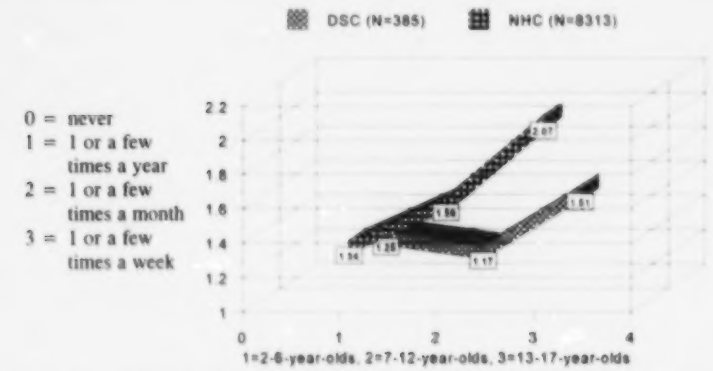

FIGURE 10. DSC- and NHC-parents' opportunities to spend leisure time together in relation to the age of the child (N = 385 and 8313, respectively)

mothers were satisfied with their family situation: the NHC-mother being very satisfied, and the DSC-mother being relatively satisfied (the main effects were the family type, $F = 41.04$, $p < .000$, and the child's age, $F = 6.96$, $p < .001$, see Figure 11). The level of satisfaction with the family situation differed among DSC- and NHC-mothers throughout their life cycles, and the difference between the two groups did not decrease as the children reached adolescence.

3.8 The mothers' satisfaction with their social contacts

The frequency of the mothers' social contacts with relatives and friends was higher among mothers of nonhandicapped children than among mothers of children with DS (the main effects were the child's age, $F = 36.38$, $p < .000$, and the type of family, $F = 60.44$, $p < .000$, see Figure 12). The results may be interpreted according to Wehn and Sommerchild (1991) who suggest that the informal social networks of mothers of children with a disability are often smaller, more intense and more closely knit. As some of the children do not develop the social skills necessary for the mastery of equal and symmetrical adolescent peer group relations, the mother is obliged to integrate the child within her own social activities. The child usually takes part in her social relations, and, consequently, the mother's social contacts may be restricted to those people who accept the child's disability.

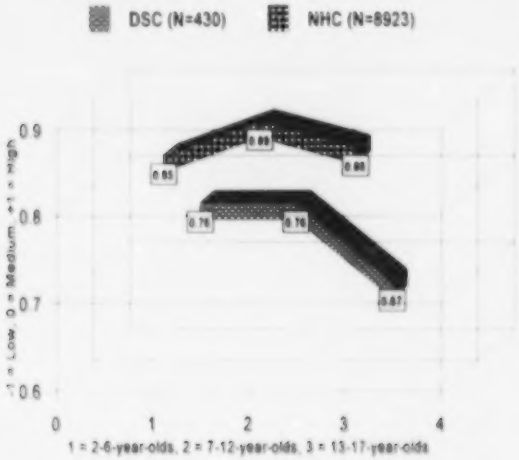

FIGURE 11. DSC-and NHC-mothers' satisfaction with the family situation in relation to the age of the child (N = 430 and 8923, respectively)

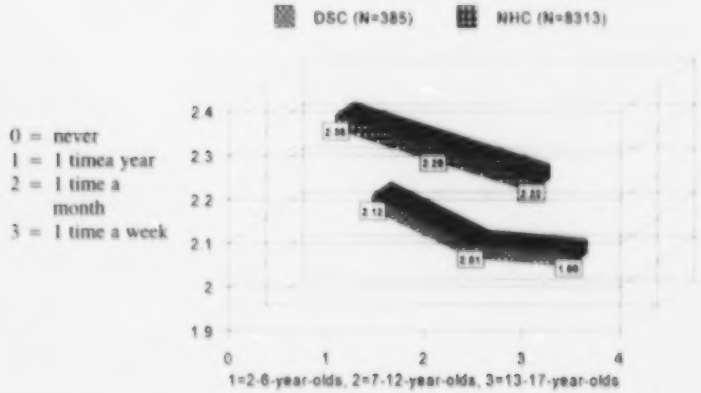

FIGURE 12. DSC- and NHC-mothers' social contacts with relatives and friends in relation to the age of the child (N = 385 and 8313, respectively)

In the present study, the child's personal social contacts and the mother's evaluation of his loneliness were investigated. The social contacts of a child with DS are fewer than those of the nonhandicapped child at the same age, and the number of peer interactions decreased during the child's adolescence (the main effects were the type of family, $F = 2093.64$, $p < .000$, the child's age, $F = 154.15$, $p < .000$, plus interaction, $F = 9.66$, $p < .000$, see Figure 13).

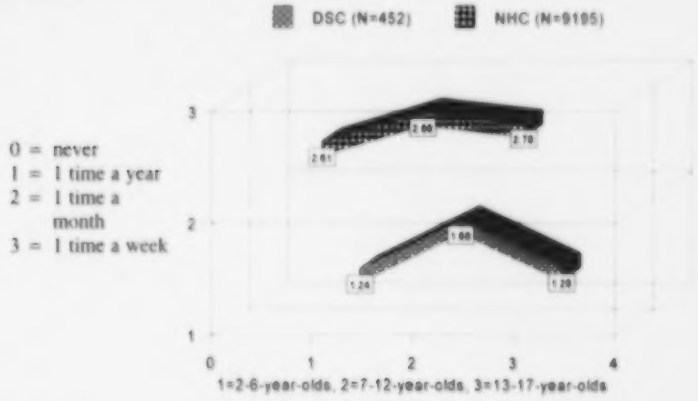

FIGURE 13. Frequency of DS- and NH-child's social contacts with friends (peer interactions) in relation to age (N = 452 and 9195, respectively)

The mothers of children with DS thought that their school-aged children were much lonelier than did the mothers of younger children with DS. Nonhandicapped children, regardless of their ages, were not regarded as lonely by their mothers (the main effect was the family type, $F = 358.88$, $p < .000$, plus interaction between the family type and the child's age, $F = 25.40$, $p < .000$).

The child with DS develops slower his self-regulatory capacities in his social activities (a kind of peer competence, de Roos 1995, 13-14) than his nonhandicapped peer. Consequently, the child with DS took part in his mother's social activities to a greater extent than adolescents in general.

Was the mother satisfied with the way her social contacts were organised?

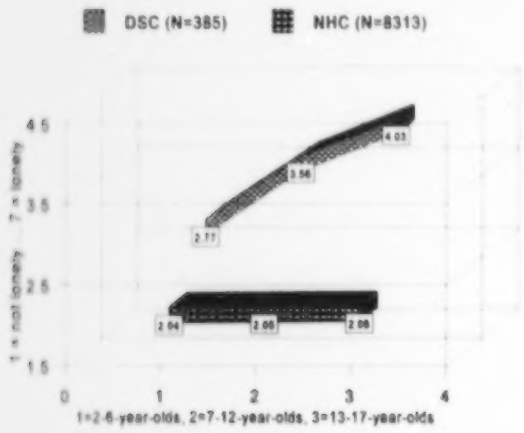

FIGURE 14. The mother's evaluation of her child's loneliness (N = 385 and 8313, respectively)

The satisfaction with social contacts was moderately high among mothers of nonhandicapped children and increased steadily as the children grew up. The satisfaction of mothers of children with DS was, on average stable but decreased as the child entered adolescence (the main effects were the family type, $F = 55.83$, $p < .000$, the child's age, $F = 26.05$, $p < .000$, plus interaction, $F = 15.76$, $p < .000$, see Figure 15). The mother of a child with DS did not seem completely satisfied with the way her social contacts were organised, depending on the child's age.

3.9 The mothers' satisfaction with their work situation

The women in the sample with children with DS were either housewives or had less full-time and more part-time work than did mothers of nonhandicapped children. It appears that the presence of a disabled child restricted the mothers' opportunities to work outside the home, and, for those who were working, the greater incidence of family illnesses (for instance, the more frequent illnesses of the child with DS) had an impact on the number of hours worked. Mothers of children with DS had more absences from work because of the children's illnesses over a three-month

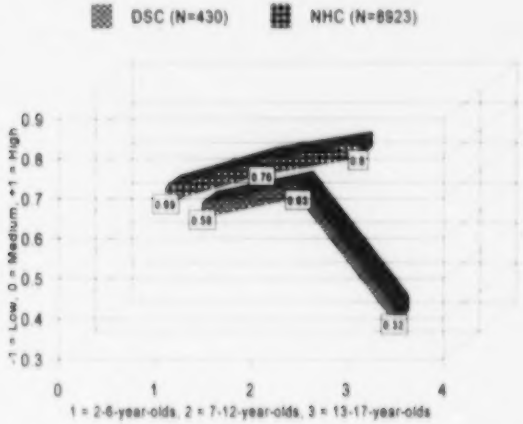

FIGURE 15. The mother's satisfaction with her social contacts (N = 430 and 8923, respectively)

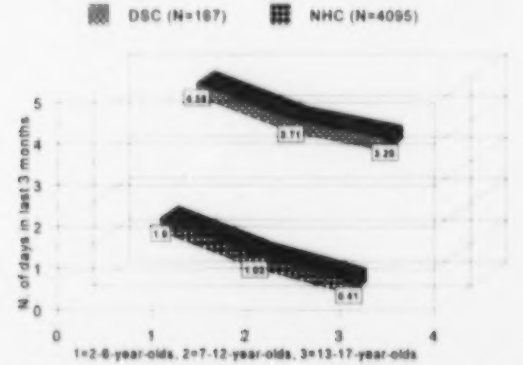

FIGURE 16. DSC- and NHC-mothers' absences from work because of children's illnesses (N = 167 and 4095, respectively)

period than did mothers of nonhandicapped children (the main effects were the child's age, $F = 72.50$, $p < .000$, and the type of family, $F = 111.18$, $p > .000$, see Figure 16), the trend decreasing for both groups, as the children became older. But the frequent illnesses of the child may sharpen the conflict between the caretaking responsibilities and the professional

demands of a qualified and/or demanding job, and, as succinctly put and analysed by the stress-researcher, Marianne Frankenhaeuser (1993, 131): *"double roles produce double stress"*.

Were the women satisfied with their work-situation? The mothers of nonhandicapped children were generally satisfied with their work-situation, and, in contrast to the mothers of the children with DS, satisfaction with their work steadily increased, as the child is grew up (the main effect was the child's age, $F = 20.62$, $p < .000$, see Figure 17). The mothers of children with DS were less satisfied and their satisfaction with the work situation actually decreased as the child entered adolescence.

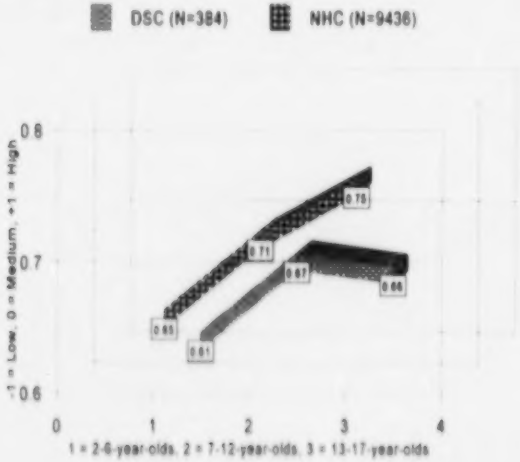

FIGURE 17. The mothers' satisfaction with their work situation (N = 384 and 9436, respectively)

3.10 The mothers' satisfaction with their state of health

The DSC-mothers reported more frequent psychosomatic symptoms, but were they satisfied with their state of health? For the both groups of mothers, the satisfaction with their state of health decreased as the years passed and psychosomatic symptoms increased (main effects were the type of family, $F = 15.67$, $p < .000$, and the child's age, $F = 10.33$, $p < .000$,

see Figure 18). But there was a steeper decline in the satisfaction of DSC-mothers with their state of health, over time, and their health actually deteriorated faster than the health of mothers of nonhandicapped children.

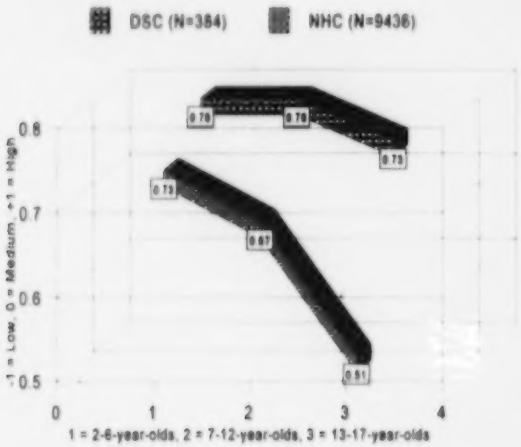

FIGURE 18. The mothers' satisfaction with their state of health (N = 384 and 9436, respectively)

3.11 The mothers' general satisfaction with their life situation

If we look at the mother's overall satisfaction with her life-situation (a sum of the variables of the mother's satisfaction with her work-situation, her family situation, the family's financial situation, her social contacts, her leisure and health), the trends for the two groups of mothers were quite distinct. Mothers of nonhandicapped children were generally satisfied with their life-situation and their satisfaction even increased as the children entered adolescence. The mothers of children with DS were moderately satisfied with their life-situation, but their satisfaction did not increase as the children grew up, and even decreased (the main effects were the type of family, $F = 62.35$, $p < .000$ and the child's age, $F = 58.89$, $p < .000$, plus interaction, $F = 12.74$, $p < .000$).

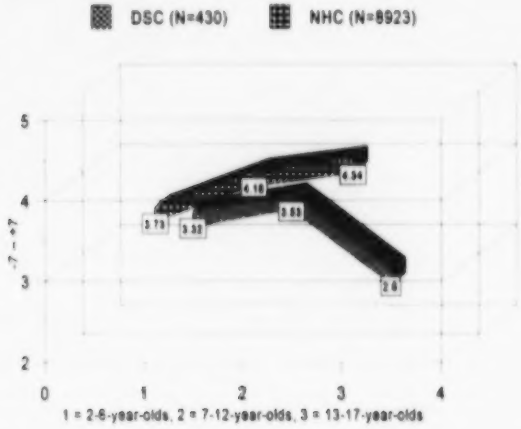

FIGURE 19. The mothers' general satisfaction with their life-situation (N = 430 and 8923, respectively)

The results indicate that there is a greater conflict for the mother of a child with DS to resolve between the extended caretaking responsibilities and her desire for alternative life-projects and social contacts. Her leisure time, both the leisure time spent alone and spent together with her partner/spouse is insufficient. She is increasingly dissatisfied with her opportunities for leisure time activities and the family situation as the child moves into puberty. She has fewer social contacts and she feels a growing dissatisfaction with them. Compared to the mother of a nonhandicapped child, she has less full-time work, and has more absences from her job because of her child's frequent illnesses. She does not become more satisfied with her work situation, even when the child grows older. Is the seemingly insoluble conflict between the caretaking responsibilities and the options for other life projects (Gustavsson 1985), that continues into the child's adolescence, a growing stressor that pervades the life-situation of the mother of a child with DS? If so, then the aim of the interventions should be to offer the kinds of services to the family that enhance the mother's chances to develop space (e.g. intervals of time) for other activities in her life at the same rate as mothers of non-handicapped children, as the children develop age-paced mastery in learning, social activities and work.

3.12 Nordic fathers – Stepping in from the periphery

According to Gustavsson (1985), in the mothers' later solutions to the conflict between caretaking responsibilities and alternative life projects, a characteristic feature was the delegation of some of the caretaking tasks either to the father or the municipal welfare systems. If the father was involved in caring for his disabled child, he would be confronted with the same conflicts as the mother, but at a far later stage in the child's development. Because there were few measurements in this study concerning the fathers, because the mothers were the respondents, the results are preliminary and inconclusive. As Table 4 shows, the percentage of long sick-leaves taken by fathers of children with DS was greater than for fathers of nonhandicapped children. A higher percentage of long sick-leaves is an indicator of more serious health problems. Thus, not only the mothers, but also the fathers of children with DS seem to have more problems with their health than parents of nonhandicapped children.

The fathers of children with DS are absent from work significantly more because of the child's illnesses than fathers of nonhandicapped children. Absences from work were most frequent when the child was 2-6-years-old (main effects were the child's age, $F = 24.47$, $p < .000$, the type of family, $F = 70.20$, $p < .000$, plus interaction, $F = 5.23$, $p < .005$, see Figure 20).

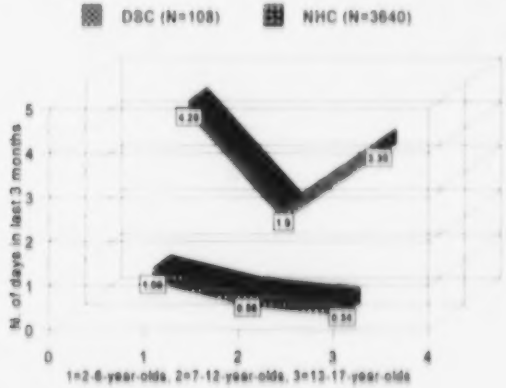

FIGURE 20. Fathers' absences from work due to child's illness (N = 108 and 3640, respectively)

Furthermore, the differences in absences from work between fathers of children with DS and the fathers of nonhandicapped children in the Nordic countries were most significant when they had children in this 2-6-year age group. In contrast to the results of a study on Swedish fathers' non-participation in the daily care of their disabled infants done by Gustavsson (1985), fathers in the present study (if the conclusion is based on the indirect measure of the fathers' absences from work because of children's illness) seemed to participate in the care of their young children, at the expense of their jobs. The presence of a child with DS did, however, affect the mother's, but not the father's, working hours.

For all three age groups of children, the fathers of children with DS also had more restricted leisure time activities especially for opportunities to:

- go to a theatre, cinema or restaurants (main effects were the type of family, $F = 119.94$, $p < .000$, the child's age, $F = 13.16$, $p < .000$, see Figure 21a)
- take part in sports (main effects were the type of family, $F = 57.46$, $p < .000$, the child's age, $F = 5.70$, $p < .003$, see Figure 21b).
- visit or be visited by relatives and friends, social contacts (main effects were the child's age, $F = 29.35$, $p < .000$, the type of family, $F = 172.30$, $p < .000$, see Figure 21c).
- participate in educational courses (main effects were the child's age, $F = 15.56$, $p < .000$, the type of family, $F = 29.14$, $p < .000$, see Figure 21d).

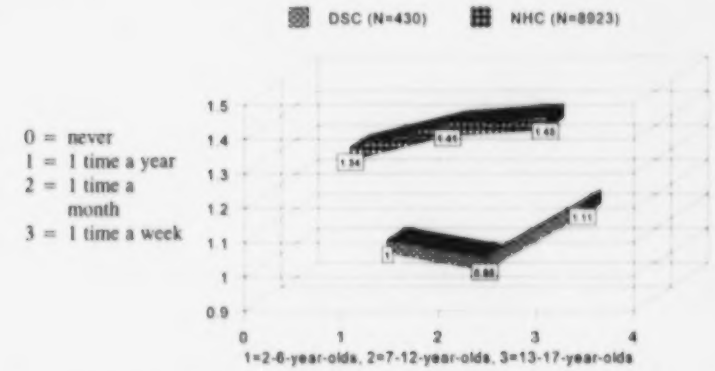

FIGURE 21a. The fathers go to a theatre, cinema, restaurants (N = 430 and 8923, respectively)

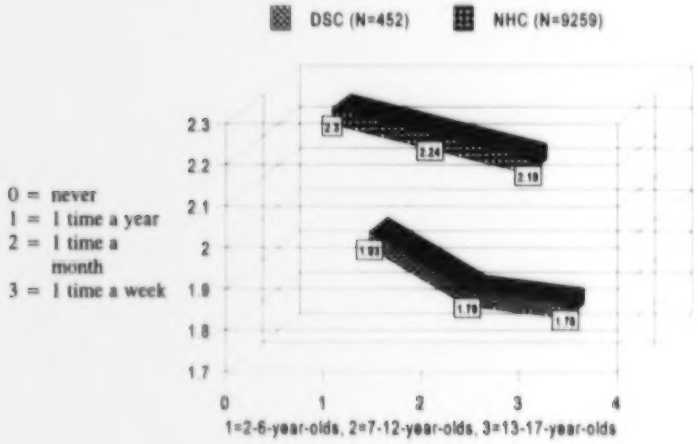

FIGURE 21b. The fathers visit or are visited by relatives or friends (N = 452 and 9259, respectively)

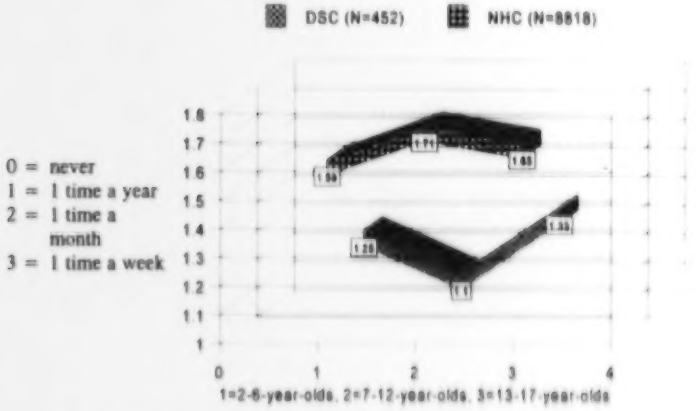

FIGURE 21c. The fathers take part in sports, athletic activities (N = 452 and 8818, respectively)

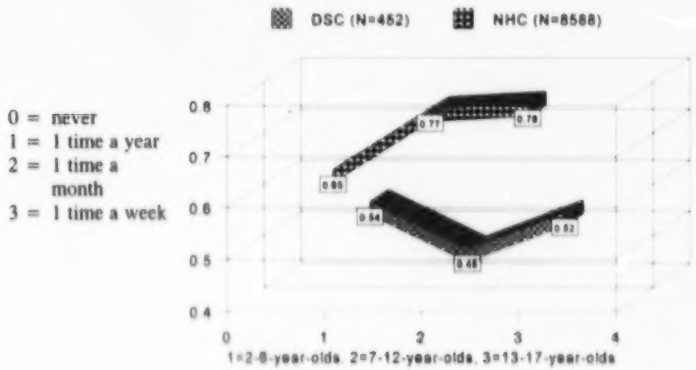

FIGURE 21d. The fathers participate in educational courses (N = 452 and 8588, respectively.

These differences between the fathers of NH- and DS-children in regard to restricted leisure time were most pronounced during the child's early school-years, decreasing during the child's adolescence. Thus, if the father's opportunities for leisure time activities and his absences from work because of the child's illnesses are used as indirect indicators of the extent to which the fathers in the Nordic countries take their part of the responsibility for child-care, the fathers seem to be quite involved in the caretaking task from their child's infancy onwards. Nordic fathers have come in from the periphery, i.e. their traditionally more marginal position in child care. Carpenter and Herbert (1995) note a similar shift in the familial role of English fathers in regard to their disabled children. In the present study, it is both the mother and the father who have restricted leisure time, due to the greater-than-average caretaking responsibilities for their disabled child and the greatest differences in availability of this time for alternative life projects between DSC-parents and parents of nonhandicapped children are seen when the children are in the 7-12-year-old age range.

3.13 The psychosomatic symptoms of the siblings

It has been argued that the stress related to the presence of a mentally disabled child affects the siblings, due in part to the stress experienced by the mother. The mother may demand too much, too soon from the

nonhandicapped sibling, especially, if the sibling is the oldest and the only sister (Cleveland & Miller 1977). This situation may be a source of stress, but, if the child is capable of handling it well, it may also result in the development of altruistic concern and a greater tolerance towards deviant behaviour (Bågenholm & Gillberg 1991). In the present study, the mothers were asked a question concerning the psychosomatic symptoms of the nonhandicapped siblings. A sum of the variables was constructed concerning these psychosomatic symptoms. In general, the level of psychosomatic symptoms of the siblings was low, although it was significantly higher for siblings of a child with DS (the main effects were the type of family, $F = 15.87$, $p < .000$, and the child's age, $F = 19.82$, $p < .000$, see Figure 22).

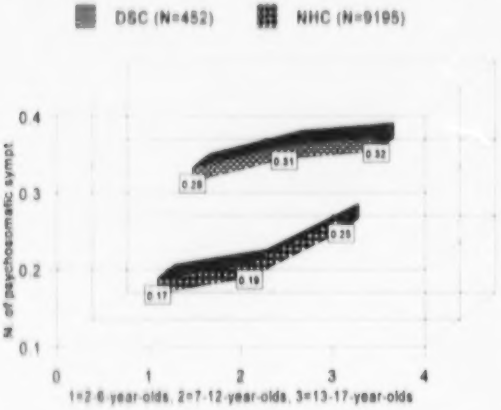

FIGURE 22. The psychosomatic symptoms of the siblings (N = 452 and 9195, respectively)

Thus, if the number of reported psychosomatic symptoms exhibited by siblings is used as an indicator of prolonged stress, siblings of a child with DS in the Nordic countries seemed to manifest a moderate stress reaction. On the basis of the data of the present study, it is not, however, possible to determine whether the source of the stress reaction arises from the differences between the demands placed on the nonhandicapped sibling and his/her actual ability to cope with the family situation.

3.14 Mothers of children with DS: Involvement in advocacy for the rights of their disabled child?

In the present study, families with a child with DS were compared to families with a nonhandicapped child (Köhler 1990). Consequently, the lifestyle of families with nonhandicapped children was implicitly used as a kind of positive standard when measuring how families function. Thus, the families of children with DS were studied in terms of what they seem to lack in accordance with a *deficit* – model of thinking (critically examined already by Basil Bernstein 1975). The families with a DS-child were not studied in terms of their own lifestyle and the coping mechanisms that are unique and meaningful for their life situation (Gallimore, Weisner, Kaufman & Bernheimer 1989).

But even in this kind of comparison, some outcomes are found that may be considered positive from a parental empowerment point of view. The mothers of children with DS were more involved in different organisations and had more contact with people who were in a position to influence decisions concerning the child and the family or to influence different societal matters in general (a sum of the variables was constructed consisting of two items: 1) *"Does the mother have a position of trust in organisations?"*, 2) *"Has she been in contact with people who can promote the rights of her child or family or larger societal decisions that affect disabled children?"*; the main effects were the type of family, $F = 211.80$, $p < .000$, and the child's age, $F = 21.41$, $p < .000$, plus the interaction, $F = 10.89$, $p < .000$, see Figure 23).

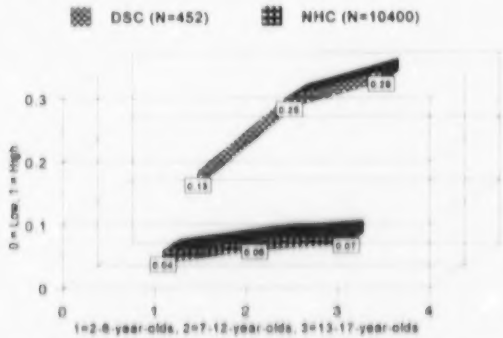

FIGURE 23. The social and political involvement of the mother (N = 452 and 10400, respectively)

The greater involvement of the mother of a child with DS in societal matters that affect the child and the family probably has to do with a position of advocacy evolving among mothers of disabled children. As Wright (1976) notes, the parents' reorientation enables them to refocus their attention from themselves to problems concerning their child as he/she is confronted with the demands of the real world. The parents might become *mission-oriented*. They certainly need this kind of orientation in order to fight for and get the services they need for their child.

Thus, the parents gradually begin to channel their energies into helping their child to solve and to overcome problems that are related to his unique way and rhythm of learning, as he confronts with the culturally-defined requirements of new developmental tasks.

4 Discussion

As this study is cross-sectional and not longitudinal, the results may also reflect age-cohort differences. There are significant SES-differences between the samples compared, especially with regard to the mothers' educational levels. The sample of families with a child with Down syndrome under-represents families with lower-than-average levels of education and SES. But these differences are not expressed in terms of typical Nordic SES-differences found in family socialisation research (Hautamäki 1982). In spite of the SES-differences between the samples compared, both the mothers and fathers of children with DS have more health problems than the parents of nonhandicapped children.

Although this is a large-scale survey study, I have, at the risk of being speculative, tried to *transcend* some of the apparent empirical connections with those presumably more essential relations that determine the developmental logic of the phenomena in question: For example, I have touched on how the difference between living in metropolitan and sparsely populated areas affects the number psychosomatic symptoms reported by mothers, and on the issues of the parents' unmet expectations inherent in chronic sorrow and the presumed narcissistic vulnerability of the parents of a disabled child. These more general theoretical theses are impossible to prove only on the basis of this study. But I will try to put forth some general theoretical guidelines for an interpretation of the results to be tested in further research.

5 Conclusions

The results indicate that bringing up a child with DS is usually relatively well managed in the Nordic countries. There is little parental discord leading to separation. The fathers in the Nordic countries have taken their part of the caretaking responsibilities of their disabled child and they seem to be quite involved in the caretaking task from their child's infancy onwards. But the presence of a child with DS does not affect the father's working hours. However, significantly fewer mothers of children with DS have a full-time job in the Nordic countries. Instead they work part-time or were full-time house-wives. Families with a child with DS have a good socioeconomic standard in comparison with the control group. With the exception of the mother's age and working hours, the demographic differences (especially the SES-differences) between the samples compared reflect differences in sampling procedures rather than real differences between the two populations. The educational and socioeconomic differences between the DSC- and NHC-samples are probably due to a slight over-representation of families from urban areas (especially Finland and Sweden) caused by the sampling procedures used for the DSC-sample.

The vast majority of mothers with a DS-child are relatively satisfied with their lifestyle and maintain an optimistic view of their children's futures. This is particularly true for mothers living in rural areas.The lifestyle of families with a child with DS in the Nordic countries is, however, circumscribed throughout the life-cycle of the family by the child's disability. The mother seems to remain as the external support system for the child's daily activities throughout his adolescence, because the child develops slower the self-regulative capacities necessary for autonomous activity. Thus, it may be difficult for the mother to resolve the conflict between the caregiving responsibilities inherent in mothering her disabled child and the options for other life projects.

Most likely, the opportunities to resolve this conflict, in part or in whole, has an impact on the stress experienced by both parents. According to the life-stage approach to family life used in the present study, it has been assumed that the parents' life-stage expectations mediate the vulnerability to the stress experienced. In other words, the experience of stress is heightened when the parents' expectations, in regard to age-typical life-events coupled to the presumed age-typical development of an average child, are not met. These recurring periods of stress and sadness have been termed as *chronic sorrow* (Wikler, Wasow & Hatfield 1981). The results of the present study

indicate that the life-stage expectations of the DSC-mothers are not necessarily met. The DSC-mothers' opportunities to take part in alternative activities are fewer than those of mothers of nonhandicapped children and do not increase at the same rate as for mothers of nonhandicapped children.

The vast majority of DSC-mothers are relatively satisfied with their life-situation, their satisfaction being, however, less than that of the NHC-mothers and it decreases as their child enters adolescence. The mothers are obliged to take an offensive role in promoting their children's rights. The greater mothering strain inherent in the DSC-mother's role (the diminishing expectations related to greater narcissistic vulnerability of the parents which forms the psychodynamic core of *chronic sorrow*, the seemingly difficult-to-solve conflict between the caretaking responsibilities and other life projects, the longer-than-average functioning as the external support system of the child's activities, the necessary advocacy role in promoting the rights of the child) may, in the long run, be a health risk resulting in psychosomatic symptoms, especially in the metropolitan areas in Finland, Sweden and Norway.

The fathers of children with DS in the Nordic countries are also characterised by a circumscribed way of life. In regard to the effects of children with DS on activities of the fathers, the results agree with those of Barnett and Boyce (1995, 122-123):

> "Fathers of a child with Down syndrome also made accommodations in their activities, although these appeared less demanding in that they required less time and paid work was unaffected. However, these fathers increased their child care time a great deal compared to the time fathers typically spend providing child care and reduced their time in social activities."

In the present study, the father has more absences from work because of the child's illnesses starting from the child's early childhood. In contrast to the results of a study done by Gustavsson (1985) on Swedish mothers and fathers, fathers in the present study seem to participate in the care of their young children. As the child grows up, the DSC-father has fewer opportunities to participate in leisure time activities than the father of a nonhandicapped child. If the father's absences from work (because of the child's illnesses) and the restriction of his leisure time activities are used as an indicator of the degree of his participation in caretaking responsibilities, one may conclude that fathers of DS-children in the Nordic countries really have taken over some of the caretaking responsibilities from the mother, thereby alleviating her situation. The number of long sick-leaves taken by

Nordic fathers also indicates that their health problems are greater than those of the fathers of nonhandicapped children.

Even if the fathers do assume their part of the caretaking responsibilities for their child, the mothers of children with DS are still, as the years go by, more strained than mothers of nonhandicapped children. Siblings of a child with DS in the Nordic countries seem to manifest a moderate stress reaction, too. To alleviate maternal strain, it is important to help the mothers solve the conflict between caretaking responsibilities and other life projects in a way that makes it possible for them to maintain their self-esteem through finding the optimal balance between their needs and the needs of the child. Each mother must develop her own priorities in such a way that she feels that she neither betrays her child nor is overly compelled to deny her own needs. Because the results of this study indicate that fathers in the Nordic countries are also involved in caring for their disabled children, the interventions should alleviate both the maternal and the paternal strain and offer services to the family that make it possible for the mother, in particular, to develop space (that is, intervals of time) for other activities in life at the same rate as mothers of nonhandicapped children do, as the children develop their age-paced mastering in learning, social activities and work. These services should ideally be tailored to each family to fit the unique cultural features of their way of life and to meet the needs as articulated by the family members themselves, as they try to work out their own meaning and ways of coping with the new and challenging situation, the task of growing up together with their disabled child.

Epilogue

Summer poem.

"When the grass grows green,
Jonas will run around
bare-naked,
without clothes,
and pick flowers,
for mum and dad,
and blueberries and raisins."

(Jonas, 5 year-old, with Down syndrome)

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